

FAMILY BEREAVEMENT SUPPORT PROGRAMME

Social Work Department

NEWSLETTER NOVEMBER 2022



The Royal
Children's
Hospital
Melbourne

“WHAT WOULD YOU TELL YOUR CHILD?”

Welcome to the November family bereavement group and our first face to face group since pre-COVID. We were very pleased to welcome parents back on site but also recognise that it is difficult for some who were able to attend the zoom groups but cannot come to RCH for a face-to-face meeting. We hope this and future newsletters go some way to helping them continue to feel part of this community.

This first on-site group was not large, with four parents attending. All expressed their appreciation of being able to meet face to face again. One parent said “**It is nice to be back with others who know how to just sit with it (grief)**”. For some of the parents present the hospital had been their child’s home or a place where they spent a lot of time and where they spent their last days. For these parents, coming back to an on-site group felt a bit like coming back to their child’s home. One parent was attending the group for the first time. His child had died suddenly and unexpectedly following a very brief and quite common illness only 6 weeks ago – an unexplainable and totally unfore-

seeable death. He came to the group to hear how others survive and to gain reassurance that he too could survive this tragedy.

The topic, ‘**what would you tell your child?**’ was inspired by a poem by Donna Ashworth:

I walked with you today, I took the longer way

I made some time to tell you all the things I didn't say,

I spoke to you so softly and so often tears just flowed.

I let you know my secrets, the stories you were owed.

We began by reading all 4 verses of this poem* and then asking the question of the group – is there anything you would say to your child if you could speak to them again? All the parents in the group felt they would tell their child how much they loved them, but they also felt that this was something they had told their child in life and they would have known they were loved. One parent said in response to the question: “**I love you. I have no regrets because I told her I love her all**

the time, always had cuddles and kisses, but I would love a chance to tell her I love her again. After six and a half years it just stops, just gone. She knew she was loved". This parent spoke of his daughter's loving personality and of her habit of coming into the bedroom in the morning and just standing by the bed until he woke up and saw her there. All the beautiful moments that would not happen again.

Another parent said: **"I would say 'I love you', but there is a lifetime of missed opportunities, I want to hear him say it back as I don't have that from him. When his siblings say it I know what they sound like and it makes me wonder how he would have sounded. I never heard his voice"**. She went on to talk about all the missed conversations, the conversations they never got to have. She told us that she still talks to him but not as much as before COVID. With home schooling and working from home it was much harder to have alone time. **"I missed the group because this was my time with him"**.

Other parents agreed that what they really felt they had missed out on was not the opportunity to say something to their child but the opportunity for their child to say something to them – what would s/he have said, what would s/he have been like, how would s/he have interacted with their siblings? All those conversations that will never happen. This mother spoke about what her baby did communicate with them in his 9 weeks of life – **"He had started to look at us prior to his passing. He smiled once and we were able to catch this on camera – the smile was a conversation back to me. I'll never know the sound of his voice"**. She went on to tell us that he now has 2-year-old twin siblings – **"It is harder now, I hear their voices and wonder what he would say, would he have pronounced things differently? I know what I would say but don't know what he would say"**.

Another parent whose child was not an infant when she died told us that he knew what she would say in so many familiar situations, when riding on the back of the bike with him, when she saw a flower **"...I know what she would say, I can hear her – I have a sense of being haunted"**. He shared a recent experience with us of waiting for her voice – **"I was reading a bedtime story to my 3-year-old. It was a book I read to her often. I got to a particular page and was waiting for her usual response, momentarily forgetting that she wasn't there. I just collapsed in tears"**. He talked to the group about his daughter and how she would talk all the time, and what a wonderful imagination she had. He told us what an amazing girl she was and how he was still expecting to hear her voice in everyday situations – **"I still expect her to be there. I want it to stop"**. All the parents in the group, regardless of how long ago their child passed away or how old they were at the time could absolutely relate to these sentiments.



A parent who had been listening to the conversation said she felt incredibly guilty about how she was in her child's final admission to the hospital. She said he was not sleeping and she was exhausted and not coping well. She remembers asking her husband to come in for the night as she was afraid she was so overwhelmed and tired that she had lost patience with their child. At the time she had no idea that this was all going to end so soon. As she listened to the experiences of the father with his daughter she said she felt guilty about her parenting of her now 10 year old child. She

had so longed for another child and she thought her parenting would be different after losing a child, that she should feel a sense of great appreciation. She told us how she gets angry and frustrated with her child at times. She does not appreciate being woken up by him early in the morning when she has a full day of work ahead. In fact, she is just like almost every other parent but somehow she expected she wouldn't be, that she would have unending patience and understanding. Another parent responded – **“Just because my child died does not take away all the normal pressures of parenting. You can't expect to be the idealised, perfect parent because of all you have gone through”**.



Another parent spoke of similar feelings with his son. He felt disconnected from him in the early period after his daughter's death, he was so engrossed in the grief for his daughter that he didn't even want to be with his son. Another parent agreed that in the early days **“I realised that you need to be selfish, you are in survival mode and you just don't have time for anyone else”**. In spite of this disconnection from other children a parent also told us that she doesn't know how she would have managed if she did not have the older sibling to get up for every day. The lack of connection to any siblings in the early days and even months of grief is a common theme in the group and one parent said that even when you are many years on in this journey there are still times when you can feel this lack of connection – **“You can still go straight back to that moment in an instant”**.

Conversation then moved to the impact of grief on partner relationships. Parents recognised that talking and communication is really important. We talked about different ways that parents grieve. Some throw themselves into work and are unavailable to their partner and any children leaving one parent to negotiate all the difficulties of parenting a surviving

child, keeping things running at home whilst trying to navigate the uncharted waters of their own grief alone. A parent told us that her partner is quite reserved in sharing his emotions – **“I have to accept the way he grieves. It is not the same as the way I grieve, but it doesn't mean he isn't grieving”**.

Returning to the parenting theme and the impact on surviving children, a parent told us that her child who died was her second child. After his death she felt all her parenting strategies were shattered. She now thinks constantly of the worst-case scenario and finds she has to teach herself to parent again – **“What's to stop it (losing a child) happening again? It happened once before, I fear it**



will happen again”. Parents do not want their children to be negatively impacted by their experiences of loss. One parent said she must tell herself children can do **“dangerous things safely”**. She told us she has to consciously stop herself from trying to wrap her children in cotton wool. She said that even though you may be overly protective there is no guarantee that it will stop bad things from happening. **“In the end there is nothing you can do. You have no control over anything”**. Another viewpoint was that you can go the opposite extreme and allow your living child to do all sorts of 'risky' things as your other child was never able to do these things.

A number of parents told us how they are hypersensitive to their other children displaying any symptoms that the deceased child had. One parent had experienced



a situation when her very young child became very unwell very quickly with croup and she was told that she could have died if the ambulance had not arrived when it did. She told us that when she hears her child breathing heavily it triggers a trauma response and she is **“thrown straight back into that moment when everything changed. It is like watching a movie, life playing out in front of your eyes”**. Other parents agreed that there are many triggers and you can't be prepared for them all.

The impact of parental grief on siblings and the way siblings experience grief was also discussed, both siblings who had been alive when their brother or sister died and those who were born subsequently. One parent talked about how differences in siblings can be hard to adjust to – their differing personalities, behaviours and ways they interact. He spoke about his children being best friends who often just played happily together and how much he was missing the joy of that. He said **“You can't replace it. You can have another child but it would never be the same”**. He has started to ask his son what he and his sister did, what their games were about. Another parent commented that the sibling's memories can help to keep that child's memory alive. They have memories and experiences that the parents don't, and you get to know your child from a different perspective through their siblings eyes. Some siblings talk about dreaming of their brother or sister. It was also noted that children are often quite comfortable talking about their sibling who died and other children also seem to just accept this – so unlike similar conversations for adults. We heard many examples of children including their deceased sibling in their conversations about their family and of other children just accepting this. One parent told us that her oldest living child is now 10 and he is noticing that some of his peers do not seem so comfortable with conversations about death and siblings in heaven as they

used to be. A parent also spoke about her child stating: **“It's not fair that I don't have a big brother”**. She feels he has a rather idealised and possibly unrealistic idea of what having a big brother would be like. One parent said that children don't experience grief in the same way that adults do. She said that her child can go from being sad about the loss of his brother and wanting to talk about him to then switching and running off to play. Other parents had also experienced this ability to sit with grief for a while but then apparently switch to a different emotional state, in their children. While some parents were regretful that their children had to learn about death and grief at such a young age, some felt that it made their children more compassionate and more able to be comfortable with death in their own life and with others. When a child at school had lost a sibling the only child in his class who was able to acknowledge his grief and his loss was another bereaved sibling. This child told his mother **“It will be harder for him as he had his brother. I have a brother but I never had him”**. He was referring to the fact that he had never met his brother in person but he was still very real to him.

Children are remembered and spoken about in their homes often and this helps subsequent siblings to build that special relationship with a sibling they never met in the flesh. Parents spoke about having lots of photos in the house and things that belonged to the deceased child. One parent told us that when her child brings friends home, they often play in his deceased brother's room. They are all very comfortable with the fact that he has a brother who is no longer alive. Parents talked about how their children reacted to their sibling's death – regression, anger, talking about death, being mean to people they love, getting very upset easily, having night terrors. Sometimes these behaviours and emotions settle down over time and sometimes they remain. A parent told us how she had sought out play therapy for her child

as he continued to display trauma responses well after the immediate months following his baby siblings' death. Children may not have an adult concept of death but they do experience grief and they are very tuned in to the emotions of the adults around them. Creativity is very helpful for children as they learn to process their emotions. People talked about using books to help talk about death to their children. Books that were mentioned as particularly helpful were: Bryan Mellonie and Robert Ingpen's *Beginnings and Endings with Lifetimes in between*, and Pat Schwiebert's *Someone Came Before You*. A parent told us they had found the Remembrance Shop useful. There was also some discussion about the pros and cons of Facebook groups and one parent told us about a Playschool episode about death. Talking to children about death can be challenging when you are in the midst of overwhelming grief yourself. Talking to children about the reasons why their sibling died can be even harder, particularly when you have no explanation yourself. A parent told us how her explanation about what happened to her child had to be tailored to the sibling's age and became more sophisticated and detailed as he became older. She commented that her third child was not as curious about the ins and outs of her brother's death. The children have different personalities and different needs for information.

Parents talked about how hard it is when there is really no explanation as to why their child had the condition they had and why they died. Some of the parents in the group discovered that their child had a particular genetic abnormality that caused the problem but these were not inherited and were random genetic variations – the question arose 'Why my child'? For others there wasn't even a genetic explanation, although one day science may find the reason – one mother is still waiting for the letter that will tell her why her child died. Another parent spoke of their difficult decision to withdraw treatment for their child. There was a chance his life could have been prolonged but no one knew if he would continue to live

for days, months or even years. He would certainly have lived with significant disability and no capacity to do things for himself. In making their decision they took many things into account including their child's experience – was it fair to prolong life for him, their other child's experience of having a severely disabled brother and the impact on their own lives. While this was a very difficult decision, they believe it was the right one for their child.

Parents in the group spoke of the dreams and expectations they had for their life and their child's life. They do not know what life would really have been like if their child had lived. It would not be the same as it is now. Some parents acknowledged that they may not have the children they have now and they could not imagine not having these children. A parent says she still thinks in lots of situations 'he should be there', but her partner says **"Why torture yourself with this"?**

Losing a child changes so many things – it is not one loss but many and the ripples of the loss spread to many. It is important to remember that siblings grieve too and to acknowledge that with them. Going back to our topic for the night – what would you tell your child? – There is nothing to say except *I love you, you are loved always*.

*The full poem, along with many other inspirational poems can be found on Donna Ashworth's website)





**IMPORTANT
INFORMATION**

Due to the ongoing risk of COVID 19 we will need to do things slightly differently from how we managed the group pre-COVID.

If you wish to attend the onsite group you will need to:

- Let us know you are planning to come by emailing:
bereavement.services@rch.org.au
- Enter via the 48 Flemington Rd entrance (Larwill entrance) or the blue or silver lifts from the car park
- Please arrive no earlier than 7.25 as it is important for group members to begin the group together.
- Wear a mask in the group

As this group is taking place at the hospital we must also abide by the basic principles of meeting face to face. Please do not attend if:

- you are unwell in any way
- you are a close contact of anyone who is covid positive
- you have tested positive to covid within the past 8 days or your symptoms have not resolved

Our letter box is Waiting!



Contributions such as responses and reflections on the groups' themes, poems, letters, songs, reviews of books that you may have found helpful, quotations from parents, grandparents, brothers and sisters and friends, feedback about this newsletter are most welcome. Share your thoughts, experiences, questions with others who are bereaved. Please forward them to:

Family Bereavement Support Programme
Social Work Department
Royal Children's Hospital
50 Flemington Road
PARKVILLE VIC 3052
Phone: 03 9345 6111
Or email: Bereavement.Services@rch.org.au

The next meeting of the
Family Bereavement Support Evening Group (face to face)

Thursday 8th December 2022 at 7.30pm

Please join us to discuss the topic:

**“Christmas, New Year and other events
catastrophes or opportunities for celebrating life and love”.**



The newsletter is always a team effort.
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Social Work Department, RCH



